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Research Article

Quality of sleep and depression in family caregivers of patients receiving palliative care

Palyatif bakım alan hastalara bakım veren aile üyelerinde uyku kalitesi ve depresyon

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Abstract

Introduction: This study aimed to evaluate the depression symptoms and quality of sleep of palliative care patients' family caregivers.

Methods: A total of 120 patients were hospitalized at the palliative care center and primary caregivers were included. Depression symptoms of caregivers was assessed by the Beck Depression Inventory (BDI) and quality of sleep with Pittsburgh Sleep Quality Index (PSQI).

Results: The mean age of 120 caregivers included in the study was 47.2±12.8 years. The mean BDI score was 10.4±7.2, and the mean PSQI score was 4.6±2.9. Significantly higher rates of depression symptoms were observed in singles than in married people (p=0.037). The healthy sleep rate of the patients whose caregiving period was 6-10 years was significantly lower (p=0.018). While 78.5% of those who received support from their families had a healthy sleep, this rate was 52.4% in those who did not receive support from their families (p=0.034). A significant difference was found between PSQI and BDI categories (p=0.004). People with moderate depressive symptoms were more likely to have poor sleep quality and long-term sleep disorders.

Conclusions: Family caregivers of patients receiving palliative care are at risk for poor sleep quality and depression symptoms. We think that the evaluation of these people in terms of the presence of depression symptoms and poor sleep quality may provide early intervention to alleviate the symptoms.

Keywords: palliative care, depression, caregivers, sleep

Öz

Giriş: Çalışmamızda palyatif bakım servisinde yatan hastalara bakım veren aile üyelerinin depresyon semptomlarının ve uyku kalitesinin değerlendirilmesi amaçlandı.

Yöntem: Çalışmaya, palyatif bakım merkezinde yatarak tedavi alan toplam 120 hastaya primer bakım veren bireyler dahil edildi. Bakım verenlerin depresyon belirtileri Beck Depresyon Ölçeği (BDI) ile, uyku kalitesi, Pittsburgh Uyku Kalite İndeksi (PUKİ) ile değerlendirildi.

Bulgular: Çalışmaya dahil edilen 120 bakım verenin yaş ortalaması 47,2 ±12,8 yıl idi. BDI ortalama puanı 10,4 ± 7,2, PUKİ ortalama puanı 4,6 ±2,9 idi. Bekarlarda evlilere göre anlamlı derecede daha yüksek sıklıkta depresyon semptomları görülmüştü (p=0,037). Hastaya bakım verme süresi 6-10 yıl olanların sağlıklı uyku oranı belirgin düşüktü (p=0,018). Ailesinden destek alanların %78,5'i sağlıklı uykuya sahip iken, bu oran aileden destek almayanlarda %52,4'tü (p=0,034). Bakım verenlerin PUKİ ve BDI kategorileri arasında anlamlı istatistiksel ilişki saptandı (p=0,004). Orta şiddette depresif semptomlara sahip kişilerde kötü uyku kalitesi ve uzun süreli uyku bozuklukları görülme oranı yüksekti.

Sonuç: Palyatif bakım alan hastalara bakım veren aile üyeleri kötü uyku kalitesi ve depresyon açısından risk altındadır. Bu kişilerin depresyon semptomları varlığı ve düşük uyku kalitesi açısından değerlendirilmesinin, semptomları hafifletmek için erken müdahale imkanı sağlayabileceğini düşünmekteyiz.

Anahtar kelimeler: palyatif bakım, depresyon, bakım veren, uyku

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Key Points

1. Depressive symptoms and poor sleep quality may be observed in primary caregivers of patients receiving palliative care. Poor sleep quality in these individuals is associated with the severity of depressive symptoms.

Introduction

Incidental to impaired quality of life of progressive patients whose prognosis are not determined receiving care in palliative care centers, the quality of life and health status of the family, family members and other caregivers who care for the sick individual are also affected [1, 2]. The burden of care of the patient affects the daily life of family members and caregivers who are responsible for caregiving. Throughout the caregiving process, the caregiver drops everything concerning her/his daily routine work and plans the whole day according to the patient, and this creates role conflict for caregivers' part [3]. Due to the care burden arising from caregiving, adverse conditions such as decreased self-esteem, disquietude, depression, sleep problems, and restriction in social life occur in caregivers' lives. These adverse situations that occur incidental to caregiving process adversely affect the quality of life, which is defined as the "general well-being" of caregivers [4].

Providing care to a patient with terminally ill is stressful and tiring [5]. Stress and burnout caused by disrupted sleep patterns as a result of family members' continuous care for the patient are important factors. Sleep is essential for physical and psychological functioning, health, and well-being [6]. Thus, adequate sleep is critical for family members to maintain their health and well-being while performing their caring duties. It has been reported that the main factors contributing to sleep disorders in caregivers are changes in sleep patterns, aggravated caregiver burden, depression, and physical health status [7].

Along with the physical problems of caregivers, the inability to provide adequate care, the inability to use appropriate materials, the symptoms of the caregiver's illness, being worried about the loss of a family member, the problems experienced between family members and poor economic conditions can lead to various psychological problems and depressive affect in caregivers [8]. Due to the increasing difficulty and responsibility of providing care to individuals with terminal illness, depression increases in caregivers as a consequence of the burden of caregiving [9,10].

Especially advanced cancer patients experience many physical and psychosocial symptoms [11] Meanwhile, the end stage of cancer or dementia is the most important stage in terms of the responsibility of family caregivers [12, 13]. Particularly, caregiver family members face many physical problems such as pain, fatigue, changes in appetite, weight loss/gain, insomnia, and changes in immune function [14].

The current study was aimed to evaluate the depression symptoms and quality of sleep of family caregivers of patients receiving palliative care.

Methods

Study population and design

A cross-sectional and descriptive study was carried out at the Samsun Training and Research Hospital Palliative Care Service between July and September 2020. The minimum necessary sample size was calculated as 120 subjects at alpha error level of 0.05 with 80% power and 95% confidence interval. The study included caregivers who were identified as the person most interested in the actual care of the inpatient in the palliative care service, who were 18 years old or older, who agreed to participate in the study and communicated in Turkish. Caregivers who did not provide continuous care to the patient, did not accept to participate in the study, and had cognitive impairment were excluded from the study. 120 caregivers who gave their consent for the research, were included in the study and the evaluation scales were applied face to face. A descriptive questionnaire consisting of 21 questions was conducted to the participants concerning their socio-demographic characteristics, the medical diagnosis of the patient they care for, the degree of affinity to the patient and the duration of care, history of psychiatric disease in the past, receiving support from the family, and chronic disease status.

Beck Depression Inventory (BDI)

Beck depression inventory (BDI) was used to evaluate the depression level of patient relatives. The BDI was developed by Beck et al. (1961) to measure the behavioral symptoms of depression in adolescents and adults [15.] A Turkish validation study was conducted [16]. It is a multiple-choice self-report scale consisting of 21 questions that determines the risk of depression and provides a four-point Likert-type measure that measures depressive level and severity. A score between 0 and 3 is given for each answer replied within the framework of the BDI. The score range varies between 0–63. According to the scores obtained, it was divided into four categories. 0-9 points correspond to no depressive symptoms, 10-16 points correspond to mild depressive symptoms, 17-29 points correspond to moderate depressive symptoms, 30-63 points correspond to severe depressive symptoms [15].

Pittsburgh Sleep Quality Index (PSQI)

Pittsburgh Sleep Quality Index (PSQI) was used to assess sleep quality. PSQI had been developed by Buysse et al. (1989) [17]. Turkish validation study was conducted by Agargun et al. and the Cronbach's alpha internal consistency coefficient was reported as 0.80 [18]. The scale provides information about the type and severity of sleep disorder in the evaluation of the sleep quality of the individual for the last month and includes a total of 24 questions. Nineteen of the questions are self-report questions and are answered by the individual per se, while five questions are answered by the individual's spouse or roommate. However, these five questions are used for clinical information only and are not included in the scoring. Self-report questions include various factors related to sleep quality. Scoring is classified as 19 items and 7 component scores. These components are subjective sleep quality (component 1), sleep latency (component 2), sleep duration (component 3), habitual sleep efficiency (component 4), sleep disturbing factors (component 5), use of sleeping pills (component 6) and daytime dysfunction (component 7). While the total PSQI score ranges from 0 to 21, the sleep quality of those with a PSQI score of 5 and below is considered as "good", and those with a score above 5 as "poor", and the overall score gives the Global Pittsburgh Sleep Quality Index score [17,18].

Ethical approval informed consent and permissions

The study protocol was approved by the Health Sciences University Samsun Training and Research Hospital Non-Invasive Clinical Research Ethics Committee. (Ethics committee approval date: 20.07.2020 number: GOKA/2020/11/10). Written informed consent was obtained from all participants included in the study.

Statistical Analysis

Data were analyzed with SPSS IBM 23.0 (SPSS Inc., Chicago, IL, USA). Study data were presented as frequency and percentages for categorical variables, mean (standard deviation) for normally distributed continuous variables, and median (min-max) for non-normally distributed data. The distribution of the data was determined using the Shapiro Wilk test. Pearson Chi-square test was used in the analysis of categorical data. Mann Whitney U test was used for non-normally distributed continuous variables in two independent groups. Kruskal Wallis test was used for non-normally distributed continuous variables in more than two independent groups. p<0.05 was considered statistically significant.

Results

79.1 % (n=95) of the participants were female. 80.8% (n=97) of them were 41 years old and above and the mean age was 47.2±12.8 years old. 60% (n= 72) were married. 65% (n=78) of them lived with their families. 79% (n=95) of them had middle income level and 68% (n=82) of them were not working. 50% of them lived in the district whereas 43% (n=52) of them lived in the province. 53% (n=64) of the participants were primary school graduates. The medical diagnosis of 35% of the patients hospitalized in the palliative service was cancer, 28% (n=34) of the patients were diagnosed with dementia, and 17% (n=20) of the patients were diagnosed with cerebrovascular disease (Table 1).

Table 1. Descriptive characteristics of caregivers and patients

Characteristics	**Caregivers (n=120) n (%)**	**Patients (n=120) n (%)**
Gender		
Female	95 (79.1)	74 (61.9)
Male	25 (20.9)	46 (38.1)
Age		
18-40	28 (23.3)	23 (19.2)
41-64	74 (61.7)	41 (34.1)
65 and up	18 (15.0)	56 (46.7)
Marital Status		
Married	86 (71.7)	72 (60.0)
Single /divorced/widow	34 (28.3)	48 (40.0)
Relationship to patient		
Brother/sister	8 (7.0)	
Spouse/partner	31 (26.0)	
Child	78 (65.0)	
Other relatives	3 (2.0)	
Employment		
Non-employed	82 (68.0)	
Employed	38 (32.0)	
Education level		
Not literate	2 (2.0)	14 (10.7)
Literate	6 (5.0)	31 (26.1)
Primary school	64 (53.0)	30 (25.4)
High school	28 (23.0)	27 (22.5)
University	20 (17.0)	18 (15.3)
Disease of patients		
Cerebrovascular disease		20 (17.0)
Dementia		34 (28.0)
Cancer		42 (35.0)
Traumatic injury		2 (2.0)
Other		22 (18.0)
Time since diagnosed (year)		
<1		53 (44.0)
1-5		58 (48.0)
6-10		9 (8.0)

When socio-demographic data and depression symptom were compared, a statistically significant relationship was obtained between marital status and depression symptoms (p=0.037). While the rate of depression is 42.9% among married people, the rate of depression is 75% among singles. The frequency of depression was significantly higher in people with less than a year of caregiving compared to those who gave care for a longer period (Table 2).

Table 2. Evaluation of sociodemographic characteristics according to Beck Depression Inventory

Variables	**Non- depressive symptom n (%)**	**Depressive symptom n (%)**	**p**[*]
Age (years)			
18-40	13 (48.1)	15 (51.9)	0.808
41-64	40 (53.4)	34 (46.6)	
65 and over	10 (55.6)	8 (44.4)	
Marital Status			
Married	49 (57.1)	37 (42.9)	**0.012**
Single /divorced/widow	8 (25.0)	26 (75.0)	
Duration of giving care (year)			
< 1	13 (29.5)	21 (70.5)	**0.018**
1-5	19 (46.3)	22 (53.7)	
6-10	20 (44.4)	25 (55.6)	
Relationship to patient			
Brother/sister	2 (22.2)	6 (77.8)	0.054
Spouse/partner	13 (42.3)	18 (57.7)	
Child	47 (60.0)	31 (40.0)	
Other	1 (33.3)	2 (66.7)	
Employment status			
Non-employed	39 (47.1)	43 (52.9)	0.220
Employed	24 (62.5)	14 (37.5)	
Education status			
Literate	2 (28.6)	5 (71.4)	0.636
Primary high school	29 (54.7)	24 (45.3)	
High school	12 (52.2)	11 (47.8)	
University	9 (52.9)	8 (47.1)	
Medical diagnosis of patients			
Cerebrovascular disease	12 (58.8)	8 (41.2)	0.857
Dementia	16 (46.4)	18 (53.6)	
Cancer	23 (54.3)	19 (45.7)	
Other	12 (50)	12 (50)	

* Pearson Chi-square test

The median value of the PSQI score differs significantly according to the duration of care for the patient (p=0.012). While the median value of PSQI was 4 for those who gave care for less than 1 year and for 1-5 years, it was 8 for those who gave care for 6-10 years. The difference stems from the higher median PSQI score of caregivers for 6-10 years compared to other groups. The median value of the PSQI score shows a statistically significant difference according to the status of receiving support from the family (p=0.003). While the median PSQI score was 4 for those who received support from their families, it was 5 for those who did not receive support (Table 3).

Table 3. Comparison of BDI and PCSQ median value with sociodemographic data

Variables	**BDI score Median (min-max)**	**p**
Gender		
Female	10 (1-35)	**0.014**[a]
Male	6 (1-14)	
Support from family		
Yes	8 (1-30)	**0.015**[a]
No	11(3-35)	
	PSQI score Median (min-max)	**p**
Duration giving care (year)		
<1	4 (1 - 11)	
1-5	4 (1 - 15)	**0.012**[b]
6-10	8 (5 - 13)	
Support from family		
Yes	4 (1 - 12)	**0.003**[a]
No	5 (1 - 15)	

a: Mann-Whitney U test; b: Kruskal Wallis test. BDI, Beck Depression Inventory; PSQI, Pittsburgh Sleep Quality Index.

When socio-demographic data and sleep quality were compared, a statistically significant relationship was found between the duration of giving care for the patient and sleep quality (p=0.018). This difference was due to the high rate of poor sleep quality in those who cared for the patient for 6-10 years. A statistically significant relationship was found between the caregiver's status of receiving support from the family and sleep quality (p=0.034). While 78.5% of those who received support from their families had a healthy sleep, this rate was 52.4% for those who did not receive support from their families (Table 4).

Table 4. Evaluation of sociodemographic characteristics according to PSQI

Variables	Good Sleep Quality n (%)	Poor Sleep Quality n (%)	p*
Relationship			0.640
Brother/sister	5 (57.1)	3 (42.9)	
Child	56 (72.1)	22 (27.9)	
Spouse /partner	23 (74.1)	8 (25.9)	
Other	2 (79.3)	1 (20.7)	
Duration of giving care (year)			
<1	25 (73.3)	9 (26.7)	**0.018**
1-5	33 (80.0)	8 (20.0)	
6-10	9 (20.0)	36 (80.0)	
Support from family			
Yes	9 (78.5)	25 (21.5)	**0.034**
No	85 (52.4)	1 (47.6)	

p*: Pearson Chi-square test

When the relationship between the presence of depression symptoms of caregivers and sleep quality was examined, a statistically significant difference was found between PSQI and BDI categories (p=0.004). According to the PSQI, good sleep quality was determined in 76.9% of people who did not suffer from depression, in 79.4% of people diagnosed with mild depressive symptoms, and in 30% of people diagnosed with moderate depressive symptoms (Table 5).

Table 5. Comparison of PSQI and BDI scores

Variables	Non depressive symptom n (%)	Mild depressive symptom n (%)	Moderate depressive symptom n (%)	Severe depressive symptom n (%)	p*
Good Sleep Quality	48 (76.9)	24 (79.4)	5 (30.0)	8 (75)	**0.004**
Poor Sleep Quality	12 (19.2)	6 (20.6)	6 (40.0)	3 (25)	
Long-term sleep disorder	3 (3.9)	0 (0.0)	5 (30.0)	0 (0)	

p*: Pearson Chi-square test. PSQI, Pittsburgh Sleep Quality Index; BDI, Beck Depression Inventory

Discussion

In our study, the depressive symptoms and sleep quality of caregivers of patients followed in the palliative care were evaluated and the relationship between them was examined. In our study, 79% of caregivers were female. Similarly, Cebeci et al. reported that most caregivers of hospitalized and cared for patients were women [19]. It has been reported that many caregivers of advanced cancer patients requiring palliative care are female [20,21]. Notably, the high representation of females among caregivers in this setting aligns with existing research highlighting the gender disparity in caregiving roles within healthcare contexts. This raises important considerations regarding the potential impact on the mental and physical well-being of these caregivers, prompting further investigation into gender-specific support mechanisms.

Within the scope of our study, 34% of the caregivers had mild, 10% of the caregivers had depressive symptoms. In the study of Ndiok et al., the risk of depression was found to be 77.9% in caregivers of cancer patients receiving palliative care [22]. Unsar et al. reported that as the caregiving burden and daily patient care duration of family members who care for cancer patients increase, their depression levels also increase. [23]. Geng et al. found a very high prevalence of depression in caregivers of cancer patients [24]. Caregivers of patients receiving palliative care are exposed to more stress than other caregivers, as the patient may exhibit severe and changing symptoms and require close and ongoing care [25,26]. This responsibility and the resulting tension can alter caregivers' physical health, social and family relationships, and trigger emotional problems.

In our study, 27% of caregivers had poor sleep quality. The quality of sleep of caregivers was low. Poor sleep quality was also found in the study of Wang'lumbar et al. [27]. Chen et al. reported that patients diagnosed with cancer and their caregivers had poor sleep quality [28]. Rigoni et. al. and Lee et. al. reported in their study that caregivers experienced sleep disorders [29,30]. In a study conducted by Chang et al. examining the sleep quality of caregivers of cancer patients, it was found that most caregivers had poor sleep quality [31]. This issue not only affects the individual's health but can also significantly impact their ability to provide effective care, potentially compromising the quality of care provided to palliative care patients. The association between depressive symptoms and specific caregiver demographics is noteworthy. The median value of the BDI score differed by gender in this study. Depressive symptoms were more common among female caregivers. Existing studies have reported that female gender is a risk factor for high psychological distress in caregivers [32,33].

In line with the study, a significant relationship was found between the marital status of the participants and depression. While the rate of depression is 42.9% among married people, the rate of depression is 75% among singles. The higher incidence of depressive symptoms among single caregivers accentuates the potential psychological burden faced by individuals lacking a support network typically provided by a partner or family structure. In our study, depressive symptoms were more common in caregivers who did not receive support from family. The impact of familial support on depressive symptoms underscores the importance of a robust support network in mitigating the mental health challenges faced by caregivers. Encouraging family involvement and establishing support structures could potentially alleviate the burden experienced by caregivers. In this study, there was no statistically significant difference once the diagnosis of the patient who is given care and the PSQI groups were compared. The percentage of poor sleep among caregivers of dementia patients was 25% and among caregivers of cancer patients the percentage of poor sleep was 28%, and it was found to be proportionally higher than other patient diagnoses. The differentiation in sleep quality based on the diagnosis of the patient is a significant revelation. Valero-Cantero et al. reported that 90.2% of caregivers of cancer patients had poor sleep quality according to the PSQI [25]. Hamamcı et al. found that the sleep quality of caregivers of Alzheimer's patients was also worse [34]. Understanding these nuances is crucial in tailoring support systems and interventions to address the specific needs of caregivers dealing with different disease trajectories. In our study, the sleep quality was lower in those who had cared for the patient for many years. The influence of long-term caregiving on sleep quality emphasizes the cumulative toll that extended periods of caregiving can have on an individual's well-being. While dedication to long-term care is commendable, it's imperative to recognize and address the potential repercussions on the caregiver's sleep patterns and overall health. A relationship between the presence of depression symptoms and sleep quality in caregivers has been determined. Good sleep quality was determined in 76.9% of those without depression, 79.4% of those with mild depressive symptoms, and 30% of those with moderate depressive symptoms. The data illustrates a clear gradient in sleep quality corresponding to the severity of depressive symptoms. Caregivers without depression exhibited notably higher rates of good sleep quality, while a decline in sleep quality was observed with the presence and increased severity of depressive symptoms. A study reported that providing palliative care to terminally ill patients may be effective in alleviating the poor psychological health of primary caregivers and improving their sleep quality [35].

Limitations

Our study has some limitations. It can be propounded that the results cannot be generalized to the whole population due to the fact that the conducted study is single center, and the sample is small. However, our study is one of the exceptional studies evaluating individual and social characteristics related to caregiving in the middle-aged adult population. For this reason, we believe that our study will contribute to increasing the awareness of health professionals by evaluating the relationship between depression and sleep quality. As a result, there is a need for follow-up studies in this area that include community-based and clinical samples.

Conclusion

It was determined that caregivers of palliative patients had mild depression and borderline level good sleep quality. In addition, it was determined that the depression levels of caregivers and sleep quality interacted with each other. In addition, it was determined that the marital status of the caregivers, the depression level, the duration of caregiving and the support from the family had significant impact on the sleep quality.

Conflict of interest: The authors declare no conflict of interest.

	Author Contributions	**Author Initials**
SCD	Study Conception and Design	TC, MC, NSY
AD	Acquisition of Data	TC, MC
AID	Analysis and Interpretation of Data	TC, MC, NSY, SM, BS
DM	Drafting of Manuscript	TC, MC, NSY, SM, BS
CR	Critical Revision	TC, MC, NSY, SM, BS

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